

# 1. AIDS Surveillance in the United States

---

## Background

In 1981, after early reports of *Pneumocystis carinii* pneumonia, Kaposi's sarcoma, and other opportunistic infections in young homosexual men in Los Angeles, New York City, and San Francisco, the Centers for Disease Control and Prevention (CDC) began surveillance for a newly recognized constellation of diseases, now termed the acquired immunodeficiency syndrome (AIDS). CDC developed a surveillance case definition for this syndrome and initially received case reports directly from health care providers and state and local health departments. As the epidemic became more widespread, state and local health departments began to assume the responsibility for AIDS surveillance, and by 1985 all states had regulations requiring physicians and other health care providers to report AIDS cases directly to the state or local health department. These health departments then share the reports with CDC, which produces the national AIDS surveillance data set.

The goals of AIDS surveillance have been to monitor both trends in AIDS cases and the scope of severe morbidity due to infection with the human immunodeficiency virus (HIV). AIDS surveillance data are used to allocate resources for patient care, target HIV prevention programs, and evaluate the impact of public health recommendations. Advances in the understanding of the epidemiology and manifestations of HIV infection and changing diagnostic practices, however, present multiple challenges to those analyzing and interpreting the AIDS surveillance data. The following are a few examples:

- A wide variety of persons are at risk for HIV, including men who have sex with men, injecting drug users, person who received a transfusion or who were tissue transplant recipients before March 1985, heterosexual partners of infected persons, children born to infected mothers, and persons with mucous membrane or percutaneous exposure to blood or body fluids of infected persons (e.g., health-care workers). Because men who have sex with other men comprise such a large proportion of the total number of AIDS cases, trends in this subgroup will overshadow those in other groups unless the data are examined separately. Analysis of data, without regard to specific subgroups, may conceal information or lead to misinterpretation of the data.
- The etiologic agent of AIDS, HIV, has been identified, and diagnostic tests for infection with this virus have been developed. As a result, the surveillance of AIDS, initially dependent on the presence of certain indicator diseases specific for the infection, was expanded in 1985, 1987, and 1993 to include additional conditions (some conditions may be less specific for HIV infection) in the presence of laboratory evidence for infection, and in 1993 to include HIV-infected persons with laboratory evidence of severe immunosuppression. The addition of these conditions to the AIDS case definition has affected trends in AIDS cases.

- Diagnostic practices have changed over time and vary geographically. AIDS is now a common diagnosis in many hospitals and clinics, and definitive diagnostic tests for manifestations of HIV infection (e.g., *Pneumocystis carinii* pneumonia or esophageal candidiasis) may not be done. HIV testing is not available for all patients and some patients may choose not to be tested. Geographic variations in diagnostic practices and surveillance procedures, and changes over time could markedly affect trends in AIDS surveillance.

## Source of AIDS Surveillance Data

CDC maintains national surveillance of AIDS through the receipt of AIDS case reports submitted by individual state and local health departments. Health departments report cases electronically through a CDC-developed microcomputer system. All 50 states, the District of Columbia, U.S. dependencies and possessions, and independent nations in free association with the United States (Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Republic of Palau, the Republic of the Marshall Islands, the Commonwealth of the Northern Mariana Islands, and the Federated States of Micronesia) report AIDS cases to CDC.

Although state and local health departments share AIDS surveillance data with CDC, the responsibility and authority for AIDS surveillance rests with the individual health departments. Like any reportable disease, the completeness of AIDS reporting reflects the aggressiveness with which these health departments solicit case reports. Historically, disease surveillance systems have been categorized as passive or active. While this dichotomy oversimplifies the description of surveillance systems, it provides a useful construct. Health departments may passively receive case reports from health-care providers, depending on health-care providers to know and comply with reporting requirements. Alternatively, health departments may actively contact and interact with health-care facilities or individual providers to stimulate disease reporting, or they may themselves assume the primary responsibility of reporting cases from large or high-volume institutions.

CDC provides funding and technical assistance to health departments to actively stimulate AIDS case reporting and has encouraged them to take an active rather than passive approach to AIDS surveillance. Through surveillance cooperative agreements supported by CDC, health departments are encouraged to identify health-care facilities that serve AIDS patients and work closely with these facilities to encourage reporting. They are also encouraged to send newsletters to health-care providers and attend professional organization meetings, and to use other data sources to identify AIDS cases, including death certificates, laboratory reports, and tuberculosis and tumor registries. States vary widely in the structure and organization of their surveillance systems and, therefore, in the completeness of their case reporting (see below).

## Case Definition

Before HIV was identified as the etiologic agent for AIDS, CDC defined a case of AIDS (for surveillance purposes) as a disease, at least moderately indicative of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to the disease. Such diseases included *Pneumocystis carinii* pneumonia, Kaposi's sarcoma, and many other serious opportunistic infections (see *American Journal of Medicine*, March 1984, pages 493-500). With identification of HIV as the causative agent for AIDS and the availability of laboratory tests to detect HIV antibody, the case definition was expanded to reflect an increased understanding of HIV infection in 1985 (see CDC's *Morbidity and Mortality Weekly Report*, June 28, 1985, pages 373-375) and in 1987 (see *Morbidity and Mortality Weekly Report*, August 14, 1987, Supplement, pages 3S-15S). These revisions applied to persons with laboratory evidence for HIV infection. Among diseases added in 1985 were disseminated histoplasmosis, chronic isosporiasis, and certain non-Hodgkin's lymphomas. Among those added in 1987 were extrapulmonary tuberculosis, HIV encephalopathy, and HIV wasting syndrome. In children, recurrent, serious bacterial infections were also added. In addition, the 1987 revision allowed certain indicator diseases to be diagnosed presumptively based on clinical presentation rather than "confirmed" by laboratory or diagnostic methods.

To be consistent with standards of medical care for HIV-infected persons and to more accurately reflect the number of persons with severe HIV-related immunosuppression who are at highest risk for HIV-related morbidity and most in need of close medical follow-up, the surveillance definition was expanded on January 1, 1993 (see CDC's *Morbidity and Mortality Weekly Report, Recommendations and Reports*, December 18, 1992). This expansion includes all HIV-infected adults and adolescents who have less than 200 CD4<sup>+</sup> T-lymphocytes/ $\mu$ L or a CD4<sup>+</sup> T-lymphocyte percent of total lymphocytes less than 14, or who have been diagnosed with pulmonary tuberculosis, invasive cervical cancer, or recurrent pneumonia. The addition of pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer in HIV infected adults and adolescents to the 23 clinical conditions listed in the 1987 surveillance definition reflects their documented or potential importance in the HIV epidemic.

While the reported incidence of AIDS increased only 3 to 4 percent as a result of the 1985 revision, the 1987 revision greatly increased the numbers of reported cases. Roughly one fourth of all adult/adolescent cases that were both diagnosed and reported in the year following the 1987 revision were reported based only on the additional criteria included in the 1987 revision. Furthermore, the proportion of cases meeting only the revised criteria was higher in Hispanics and non-Hispanic blacks than in non-Hispanic whites, higher in heterosexual injecting drug users, and lower in men who have sex with men. The 1993 revision has had substantial impact on the number of reported cases. The immediate increase in case reporting is largely attributable to the addition of severe immunosuppression to the definition; a smaller impact is due to the addition of pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer, since many persons with these diseases will also

have a CD4<sup>+</sup> T-lymphocyte count of less than 200 cells/μL. Early effects of expanded surveillance will be greater than long-term effects because prevalent as well as incident cases of immunosuppression were reported following implementation of the expanded surveillance case definition. In subsequent years, the effect on the number of reported cases is expected to be much smaller. Due to the large number of cases reported based on criteria in only the revised case definitions and to the inconsistent use of the revised case definitions in different populations, analyses of trends in AIDS cases must take these revisions into account.

## Case report form

Separate case report forms are used for pediatric patients (patients less than 13 years of age at the time of diagnosis) and adult/adolescent patients (patients 13 years of age or older at the time of diagnosis). Although the forms are very similar, the pediatric form includes risk factor information on the child's mother. These forms are completed by the health care provider or by the AIDS surveillance staff in the local or state health department. In addition, a laboratory report of an AIDS-defining condition sent to health departments may initiate a case report. In these cases, follow-up with the health-care provider is required to obtain complete information.

Names are retained by the state or local health department and are converted to an alpha-numeric code called "soundex" for use by CDC. CDC does not receive names of persons with AIDS. Because more than one state may report an individual case, CDC screens reported cases by soundex code, date of birth, sex, and state of residence to cull presumed duplicate reports. States also cooperate in this process by reporting out-of-jurisdiction cases to the patient's state of residence.

The variables available on the AIDS data set are listed in section 2. However, a few deserve special comment.

- *Vital status.* Patients survive for a variable amount of time following the diagnosis of AIDS. Because death usually occurs after the initial report to CDC, case reports may not be updated to reflect the change in vital status. As a result, reporting of deaths among AIDS patients may be incomplete. However, states are encouraged to perform periodic reviews of state death registries to identify unreported cases, and to update vital status of known cases. In addition, 16 states participate in a special project to match their case registries to the National Death Index to assess the completeness of reporting and to identify deaths among cases that died out-of-jurisdiction.
- *Exposure category.* Some patients may have more than one mode of exposure to HIV. For surveillance purposes, AIDS cases are counted only once in a hierarchy of exposure categories (see section 2). Persons with more than one reported mode of exposure are listed in the category that appears first in the exposure hierarchy, except for men with both

a history of sexual contact with other men and injecting drug use. They make up a separate exposure category.

- *Diseases indicative of AIDS.* Patients may develop additional conditions indicative of AIDS after their initial AIDS diagnosis. The case report form may not be updated to reflect additional conditions. Therefore, proportions of patients with the various AIDS-indicator condition should be considered minimal estimates. Some persons reported as meeting only the immunologic criteria may have concurrent or prior opportunistic infections that are not included in the case report. Therefore, cases reported as meeting only the criteria added to the case definition in 1993 may include persons who meet the criteria in 1987 definition.
- *Date of diagnosis.* CDC collects dates of diagnosis for each AIDS-indicator disease, and, for patients with severe immunosuppression, the date of the CD4<sup>+</sup> T-lymphocyte test. From this information, a single date of diagnosis is calculated for each patient; this is the earliest of these dates.

## Delay in Reporting

The timeliness of AIDS case reporting to CDC is dependent on a number of factors. These include the volume of cases reported from a state or locality, the cooperation of health-care providers and medical institutions, the availability of staff to complete case report forms, and changes in the case definition. In many instances initial case report forms are incomplete and require additional follow-up by state and local health department staff, including reviews of other record systems and contact with health-care providers.

Before the implementation of the 1993 AIDS surveillance case definition, about 55 percent of all cases were reported to CDC within 3 months of the date of diagnosis, but about 20 percent were reported more than a year after diagnosis. Delays vary widely among exposure, geographic, racial/ethnic, and age categories. They are substantially longer for pediatric cases and for transfusion-associated cases in adults. Because retrospective reporting of persons who met the 1993 criteria in previous years was permitted, implementation of the 1993 definition has been associated with an increase in the median interval between date of diagnosis and date of AIDS case report. During the first 3 months of 1993, persons reported with conditions added in 1993 had a median interval between date of diagnosis and date of report of 9 months, and persons with pre-1993 conditions reported in the first quarter of 1993, 5 months. The distribution of reporting delays has been shifting substantially each quarter since January 1993 as the initial effect of the expanded case definition wanes. Due to the reporting delay, the number of cases diagnosed during any period often exceeds the number reported during that period. This is particularly important in examining trends over time, since many cases in recent periods of time will not yet be reported.

To account for delays in the reporting of cases and delays in reporting of deaths, the variables *adjwgt* and *dth\_wt* have been added to the data set. These variables may be used to weight each case on the data set and obtain either adjusted case counts or adjusted death counts. For example, summing *adjwgt* for cases would estimate the number of cases diagnosed through the time period covered by the data set that will eventually be reported to CDC. To use these variables, you must select one of the adjustment weight options from the Setup menu. Once you turn on one of these options, all subsequent tabulations you request will be adjusted for the selected reporting delay. Note that computed death weights take into account delays in reporting of both cases and deaths. The adjustment weights and resulting tabulations are not reliable for cases diagnosed or deaths occurring during the most recent 6 months.

## Effect of CD4 Reporting on AIDS Case Trends

As a result of the case definition change in 1993, trends in AIDS case counts show an artifactual peak early in 1993, even after adjustment for reporting delays. To examine trends over time using a constant case definition, i.e., diagnoses of opportunistic illnesses that were included in the 1987 or the 1993 case definition, CDC has developed methods that estimate future incidence of 1987 or 1993 definition opportunistic infections for cases that meet the 1993 immunologic (CD4) criteria only. These estimates show that the number of diagnoses of AIDS-defining opportunistic infections has increased during 1992 and 1993 by approximately 2 percent and 3 percent, respectively (see *Morbidity and Mortality Weekly Report*, November 18, 1994).

## Early Reporting Dates

Before 1990, CDC occasionally received reports on patients before they met the CDC AIDS case definition. If such patients were later diagnosed with AIDS, the diagnosis date on their record (indicating when the patient first met the CDC definition) would be after the report date (when CDC first received information about the patient). Such records should be excluded from certain analyses, such as survival analysis and analysis of reporting delays. CDC's AIDS surveillance data base no longer receives reports on patients who do not meet the AIDS case definition.

## Follow-up of Reported AIDS Cases

AIDS case records maintained at CDC contain all information reported to date from state and local health departments. As patients progress through their illness, additional diseases and conditions may be reported, or the patient's vital status may change. However, not all health departments have the resources to routinely follow-up patients for additional information, including vital status. For this reason and because many patients move out of the

reporting health department's jurisdiction, CDC records do not always contain all current information for each patient.

AIDS cases reports that do not include mode of HIV exposure information are routinely followed up by state and local health departments. As of September, 1993, mode of exposure information has been identified for 76 percent of investigated cases. An additional 20 percent of cases were closed with incomplete information because the patient died, declined interview, or was lost to follow-up; 4 percent of cases remained without a reported risk for HIV infection (see Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, 1993;5(no.3):17). The demographic profile of persons who remain without risk information is more similar to that of other persons reported with AIDS than with the general U.S. population.

## Evaluation of AIDS Surveillance

Cases of AIDS may not be reported to CDC for a variety of reasons. The diagnostic tests needed to confirm the diagnosis of certain AIDS-indicator conditions may not be performed, or physicians and hospital personnel may fail to report cases to the health department. Further, some patients with HIV disease may be ill or die from diseases or conditions not included in the current AIDS surveillance definition or from causes unrelated to their HIV infection.

Both CDC and state and local health departments have commissioned a variety of studies to evaluate the completeness of AIDS surveillance. Most evaluation projects have used alternate data resources that are independent of routine case-finding, such as death certificates, hospital discharge records, and laboratory records. Individual records from these alternate sources have then been matched against records in AIDS surveillance data bases. Evaluation projects have varied in size and scope (e.g., varying numbers of ICD-9 codes from death certificates or computerized discharge records), geographic area covered, detection of both inpatient and outpatient cases, and time frames. In general, evaluation studies suggest that reporting of AIDS cases is fairly complete; but, depending on the setting and evaluation method used, the level of reporting completeness may vary. High-prevalence areas for AIDS appear to have more complete reporting than low-prevalence areas. Following implementation of active case-finding under the 1987 case definition, with funding support from CDC, completeness of case reporting increased in most areas and was estimated to be about 85 percent complete nationwide. However, completeness of reporting under the 1993 case definition has not yet been evaluated. Such studies are currently in development.

## Summary

Public health surveillance represents an ongoing and regular collection, analysis, interpretation, and application of health data for disease prevention and control. AIDS surveillance, like other national surveillance efforts, depends on health-care providers and the state and local health departments and, thus, requires a balance between information needs versus practical limitations. AIDS surveillance in the United States represents an unprecedented public health enterprise and has achieved an unusually high degree of completeness. In addition, surveillance has changed as understanding of AIDS and HIV infection have grown. Users of the public information data set should be familiar with the characteristics of public health surveillance in general as well as with the evolution of AIDS surveillance.